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Shortened and Culturally Appropriate HIV Stigma Scale for Asians Living with HIV in the United States: Psychometric Analysis



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Instruments to measure HIV stigma in people living with HIV in the United States or in Asia may not be sensitive enough to capture the stigma experienced by Asians living with HIV (ALWH) in the United States. Our purpose was to adapt the shortened Berger Stigma Scale to be culturally appropriate for ALWH in the United States. We conducted a mixed-method study (i.e., five in-depth face-to-face interviews, six subject matter expert reviews, two focus groups [n = 11]) to generate new scale items and a cross-sectional survey (n = 67) to evaluate the psychometric properties of the adapted scale called Stigma Scale for ALWH. The scale contains 13 items with three subscales (personalized stigma/disclosure, negative self-image, public attitude) with good reliability ($\alpha = 0.92$ overall) and validity. We describe the Stigma Scale for ALWH that is culturally appropriate to measure HIV stigma experienced by ALWH in the United States.

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Key words: Asians living with HIV, culturally adapted scale, HIV, psychometric analysis, stigma scale

Asians are the fastest-growing racial group in the United States (Lopez, Ruiz, & Patten, 2017). The latest U.S. HIV surveillance report showed that the

annual rate of HIV diagnoses increased in the Asian population, while rates decreased in African Americans and Caucasians and remained the same in Hispanics from 2011 through 2015 (Centers for Disease Control and Prevention [CDC], 2017a). Moreover, about one in five Asians living with HIV (ALWH) do not know their HIV status, and Asians are less likely to receive HIV-related health care compared to Caucasians (CDC, 2010, 2017b).

Several barriers delay HIV testing and related health care for ALWH in the United States. One barrier is HIV stigma, which is characterized as prejudice against, discrimination toward, and discrediting people living with HIV (PLWH) and the groups or communities they associate with (Herek & Capitanio, 1997; Koh, 2014). HIV stigma

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is rooted in multiple factors; some causes are universal (e.g., fear of HIV contagion), but others vary from culture to culture or population to population (Hong et al., 2008; Valdiserri, 2002). It might also differ based on societal values and beliefs (Parker & Aggleton, 2003). Predictors for HIV stigma in ALWH include psychosocial stress, including negative self-worth, perceived interpersonal insecurity, and financial insecurity (Kang, Rapkin, Remien, Mellins, & Oh, 2005).

Several scales to measure HIV stigma have been developed (Berger, Ferrans, & Lashley, 2001; Jimenez et al., 2010). The Berger Stigma Scale (Berger et al., 2001) is commonly used and has been tested for PLWH in the United States (Buseh, Kelber, Stevens, & Park, 2008; Jimenez et al., 2010). The scale has also been shortened for African American youth living with HIV and culturally adapted for Spanish-speaking populations; however, the scale has not been culturally adapted for ALWH (Jimenez et al., 2010; Wright, Naar-King, Lam, Templin, & Frey, 2007).

Stigma scales for PLWH in Asia have been developed and validated in Chinese PLWH and other subsets of Asian groups outside the United States (Apinundecha, Laohasiriwong, Cameron, & Lim, 2007; Xu, Sheng, Khoshnood, & Clark, 2017). Because the majority of ALWH in the United States are foreign-born (CDC, 2012), validated stigma scales in ALWH outside the United States may capture the stigma experience of ALWH in the United States better than validated scales in PLWH in the United States. However, stigma is related to culture as well as to other factors such as the prevalence of HIV in the region. In low HIV prevalence regions, higher rates of HIV stigma have been reported because of less tolerance for HIV and greater fear of contracting HIV compared to high HIV prevalence regions (Cao et al., 2010; Zukoski & Thorburn, 2009). Thus, the stigma scale developed for Asian populations outside the United States might not be sensitive enough to capture HIV stigma experienced by ALWH in the United States.

Studies using a culturally adapted scale for ALWH in the United States have been missing from the literature. To understand the type and level of HIV stigma experienced by this population, a stigma scale that is

culturally appropriate and psychometrically sound for Asian populations is needed.

The purposes of our study were (a) to describe a new culturally adapted scale to measure HIV stigma in ALWH that was adapted from the shortened Berger Stigma Scale, and (b) to test its reliability and validity with a sample of ALWH in the United States.

Methods

We used a mixed-method approach. The study included three phases: Phase 1 – five face-to-face interviews with ALWH for item exploration, Phase 2 – reviews of items by six subject matter experts and assessments of the adapted scale's content validity by focus groups comprised of ALWH ($n = 11$), and Phase 3 – an evaluation of the scale's psychometric properties using cross-sectional data ($n = 67$). The Institution on Human Research at the University of California, San Francisco, approved all phases of the study.

Study Phases

Phase 1: Item exploration. To identify ALWH experiences with HIV-related stigma, in-depth semi-structured face-to-face individual interviews were conducted. Each interview was held in a private room and took approximately 1 hour. A semi-structured interview guide was used to explore (a) the influence of ALWH societal values, beliefs, and culture on study participant perceptions of HIV risk behavior prior to being diagnosed, (b) the impact of how they sought HIV-related care, and (c) their current experiences of living with HIV. Further, participants were asked about fears and experiences with HIV-related stigma from their families and communities (e.g., *Could you tell me why you did not voluntarily seek HIV testing prior to finding your HIV status?*). Based on interview findings, we then conducted an intensive review of the literature to supplement information from the interviews. Finally, using the findings, we generated potential items related to HIV stigma experienced by ALWH.

Phase 2: Instrument adaptation and content validity. The purpose of Phase 2 was to adapt the existing

stigma scale by adding new items that emerged from Phase 1, and to assess content validity and acceptability of the adapted scale with subject matter experts and focus groups of ALWH. The subject matter experts were chosen based on their clinical or research experiences with ALWH and their publications. We first contacted them via e-mail or by phone, and if they agreed to review, the scale and instructions were sent via e-mail.

First, potential new items for the Stigma Scale for ALWH were reviewed by subject matter experts to assess the scale's content validity. After the items were modified as needed, a draft of the Stigma Scale for ALWH was assessed for face validity and acceptability in two focus groups of ALWH. Participants in the first focus group were asked about the clarity of the wording and whether the new items captured the stigma they had experienced. The second focus group confirmed the final draft. Each focus group lasted about 1.5 hours. The scale was modified as needed at each step.

Phase 3: Evaluation of psychometric properties. In this phase, we established the validity and reliability of the adapted scale. We used data from a cross-sectional survey that included the Stigma Scale for ALWH and sociodemographic questions.

Participants

All phases of our study took place in an HIV-related community-based organization in San Francisco. The organization provided services, including HIV health care, to uninsured and underinsured ALWH. We recruited participants from support groups or the waiting room in the clinic. Participants were also referred by their health care providers, social workers, and peer advocates. Criteria for inclusion for all phases were (a) self-identify as infected with HIV, (b) self-identify as Asian, (c) 18 years of age or older, and (d) able to speak and read in English. For Phase 1, in addition to these criteria, participants had to identify as being diagnosed with HIV through unintentional testing (e.g., opt-out testing in an emergency department, having an AIDS diagnosis, or receiving an HIV diagnosis through prenatal care). We established the criterion of unintentional testing because individuals who delayed being tested

for HIV prior to their HIV diagnosis were likely to have faced barriers to accessing HIV care and experienced HIV stigma (Valdiserri, 2002). For Phases 2 and 3, in addition to the above criteria, participants had to have disclosed their HIV status to at least one other person because the 10-item stigma scale contained items regarding others' reactions to disclosure (Wright et al., 2007). We recorded all interviews with a digital voice recorder and took field notes with permission from the participants. We transcribed the interviews, and ATLAS.ti Version 6 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to analyze the interviews.

Measures

Participants in all three phases answered sociodemographic questions. Additionally, participants in Phase 3 completed the Stigma Scale for ALWH, the Self-Reported Health Status Scale, and the abbreviated Suinn-Lew Asian Self-Identity Acculturation Scale (Suinn, Ahuna, & Khoo, 1992; World Health Organization, 1996).

Stigma Scale for ALWH. We used a 10-item stigma scale developed by Wright and colleagues (2007), which was shortened from the 40-item Berger Stigma Scale (Berger et al., 2001). Because the majority of ALWH in the United States are foreign-born and speak English as a second language (CDC, 2012), the burden of a 40-item scale could be an obstacle for this population (Berger et al., 2001). The shortened scale (Wright et al., 2007) has four subscales: personalized stigma, disclosure, negative self-image, and public attitudes. The 10-item stigma scale has been validated and has good construct validity and reliability on each of its subscales ($\alpha = 0.72-0.84$) in minority youth living with HIV (Wright et al., 2007).

Self-Reported Health Status Scale. Participants were asked to rate their current health status with one question, *How would you rate your health status?* The question was adapted from the item used by the World Health Organization (1996). The response was measured on a 7-point Likert scale anchored with responses, *very poor* (1) to *excellent* (7). The single item had satisfactory levels of validity and reliability,

reduced participant burden, and eased interpretation of the scale (Bowling, 2005).

Abbreviated Suinn-Lew Asian Self-Identity Acculturation Scale. The abbreviated Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA) was applied to measure acculturation (Suinn et al., 1992). The abbreviated SL-ASIA includes 19 multiple-choice questions (Suinn et al., 1992). Multiple-answer choices were formatted on a 5-point Likert scale. In scoring the scale, the values for all 19 items are totaled. Scores ranged from 19 to 95 for our study. Low scores reflected low acculturation (high Asian identification) and high scores reflected high acculturation (high Western identification). The scale achieved good reliability in our study population (Cronbach's $\alpha = 0.93$).

Analysis

Phase 1: Item exploration. We used the grounded theory method developed by Glaser and Strauss (1967) to guide and analyze interviews. Each in-depth interview was followed by coding; the codes were then categorized into larger concept areas and themes that were examined with subsequent interview data (Holloway & Wheeler, 2002). We continued these processes until all discrepancies in themes were resolved. The themes that emerged from the interviews were confirmed by the literature review. We then generated three items to be added to the new scale based on the themes (Charmaz, 2006; 2007).

Phase 2: Instrument adaptation and content validity. Subject matter experts reviewed these three items with the Content Validity Index by Waltz and Bausell (1981). The index has a 4-point ordinal scale response with a range of 1 to 4 (Waltz & Bausell, 1981). A higher number indicated that the item was more relevant to the domain of interest addressed by a scale (Waltz & Bausell, 1981). We calculated a score (possible range = 0 to 1) by counting the number of subject matter experts who rated the item 3 or 4 points and then divided that number by the total number of subject matter experts. The score should be no lower than 0.78 to establish content validity (Waltz & Bausell, 1981).

Phase 3: Evaluation of psychometric properties. We applied the adequate rule of thumb, a person-to-item ratio of 5:1, to determine the sample size for a cross-sectional study (DeVellis, 2003; Nunnally & Bernstein, 1994). Exploratory factor analysis with varimax rotation examined the construct validity of the scale and determined the best items for the final scale. To determine meaningful factors and extraction of items, factors were evaluated based on (a) whether they met a criterion of eigenvalue > 1 , and (b) breakpoints on a Scree Test (plotted graph) of eigenvalues (Kleinbaum, Kupper, & Muller, 1998). We considered that a variable was highly correlated with a particular factor and kept it in the scale if loading values were equal to or more than 0.55 for that factor and less than 0.55 for others (Comrey & Lee, 1992). Each factor was labeled as necessary. We computed Cronbach's α (Nunnally & Bernstein, 1994) to establish internal consistency and reliability of the overall scale and subscales of the 10-item stigma scale and the Stigma Scale for ALWH.

To establish construct validity, we used the convergent and divergent validities (Nunnally & Bernstein, 1994). Previous studies have shown that HIV stigma was negatively associated with self-reported general health status (Emlet et al., 2013) and acculturation (Rajabiun et al., 2008; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012), but not associated with being a high school graduate (Loutfy et al., 2012). For convergent validity, Pearson correlation coefficients between the Stigma Scale for ALWH and Self-Reported Health Status Scale or SL-ASIA were evaluated. By contrast, a linear regression was applied to assess the relationship of the Stigma Scale for ALWH and education (high school graduate) for divergent validity. All analyses were performed with IBM SPSS Statistics v.21 for Windows (IBM, Armonk, NY).

Results

Phase 1: Item Exploration

We interviewed five ALWH. The mean age of participants was 48.2 years ($SD = 4.8$). Four participants were male. The participants included three

Vietnamese, one Filipino, and one Indonesian. All were born in Asia and lived in the United States for an average of 24.4 years ($SD = 6.6$). Analysis of the interviews resulted in three major thematic areas: (a) HIV disclosure: “They (family) don’t need to know all sometimes ... I don’t want my mom sad.”; (b) family reactions: “I don’t go there (Indonesia) to visit because family don’t welcome me. They tell me I’m not the part of their family. [They said] ‘You are not welcome to my family anymore’”; and (c) gossiping: “I’m not sure my parents know [I have HIV from gossiping in community]. They don’t talk about it ... we never tell about HIV.” We confirmed that these themes were common concerns among ALWH in the published literature (Kang, Rapkin, & DeAlmeida, 2006; Yoshioka & Schustack, 2001). We developed one potential statement to represent each theme: (a) HIV-disclosure: “I did/do not tell my parents my HIV status because I do not want them to think I am not a good kid anymore.”; (b) family reactions: “I feel more distance from my family since I disclosed my HIV status to them.”; and (c) gossiping: “I have somebody who might know my HIV status, but I am afraid to ask if he/she knows.”

Phase 2: Instrument Adaptation and Content Validity

These potential statements were assessed by six subject matter experts who were doctorally prepared clinical and/or research experts in diverse content areas such as research methods, HIV stigma, and Asian studies (e.g., primary care providers and a research psychologist who provided care in an ALWH-focused clinic). Five subject matter experts scored 4 points and one subject matter expert scored 3 points on all three statements. Therefore, scores on the Content Validity Index for all three statements were 1.00, which indicated good content validity.

A total of 11 ALWH participated in two focus groups. Two participants from Phase I also participated in one of two focus groups. The mean age of participants was 46.8 ($SD = 2.4$) years of age for the first focus group and 48.7 ($SD = 6.1$) years of age for the second. The sample consisted of participants who were either male ($n = 9$) or male-to-female transgender ($n = 2$). About one-third of

participants ($n = 4$) were Filipino; others were Indonesian ($n = 3$) and Chinese ($n = 2$).

Feedback from participants at the first focus group ($n = 4$) included that they preferred the use of more specific terms for describing a person (e.g., family, friend) instead of a generic term such as somebody. Participants reported concerns about the lack of HIV knowledge in their communities and among their families and friends. They believed that people who had misperceptions about HIV (e.g., HIV can be easily transmitted by sharing utensils or toilets) were more likely to stigmatize them compared to those who had knowledge of HIV. Participants expressed the importance of including a statement about this issue in the new scale. After the first focus group and consultations with subject matter experts, potential statements were revised to: (a) *I disappointed my family and feel more distant from them since telling them I have HIV*, (b) *I have a friend or family member who might know I am HIV positive, but I am afraid to ask and find out for sure*, and (c) *Most people do not have enough HIV knowledge to understand me*. At the second focus group, participants ($n = 7$) reviewed the new stigma scale with the new statements plus the 10 items taken directly from the 10-item stigma scale. Participants in the second focus group all agreed that the new scale captured the HIV stigma they had experienced.

Phase 3: Evaluation of Psychometric Properties

Sixty-seven ALWH who met the inclusion criteria completed a self-administered survey. All 11 ALWH who were in Phase 2 took the survey. The mean age was 44.4 ($SD = 9.5$) years of age (see Table 1). More than one-third of participants (44.8%) were Filipino. The majority were born in Asia (59.7%). More than three-quarters were male (77.7%) and reported they contracted HIV through having sex with men (79.1%). Approximately two-thirds of participants (62.6%) reported less than or equal to \$20,000 (USD) in household annual income before taxes.

Exploratory factor analysis with varimax rotation found that the revised 13-item scale had three factors, whereas the original 10-item stigma scale had four factors (Table 2). The 13 items loaded on one subscale as opposed to two, personalized stigma and

Table 1. Sociodemographic and Self-Reported Health Level Scale for Phase 3 ($N = 67$)

Sociodemographic	% (n), $M \pm SD$
Age, years	44.4 \pm 9.5
Asian ethnicity	
Chinese	11.9 (8)
Filipino	44.8 (30)
Japanese	11.9 (8)
Vietnamese	10.4 (7)
Other	21.0 (14)
Generation	
1st generation (born in Asia)	59.7 (40)
2nd generation	25.3 (17)
3rd generation	7.5 (5)
Other	7.5 (5)
Gender	
Female	10.4 (7)
Male	77.7 (52)
Trans woman	11.9 (8)
HIV exposure category	
MSM	79.1 (53)
Heterosexual contact	1.4 (1)
IVDU	4.5 (3)
IVDU + MSM	7.5 (5)
Other/unknown	7.5 (5)
Household annual income	
\leq \$20,000	62.6 (42)
\$20,001-40,000	19.4 (13)
\$40,001-75,000	6.0 (4)
Don't know/decline to state	12.0 (8)
Mean self-reported health level ^a	4.9 \pm 1.7
1: very poor	4.5 (3)
2	3.0 (2)
3	11.9 (8)
4	22.4 (15)
5	17.9 (12)
6	17.9 (12)
7: excellent	22.4 (15)

Note. MSM = men who have sex with men; IVDU = intravenous drug user.

a. Possible ranges from 1 (*very poor*) to 7 (*excellent*).

disclosure, in the original scale. We combined these subscales and renamed the subscale, personalized stigma/disclosure, in the revised version. Two of the new items loaded on the personalized stigma/disclosure subscale, while the last remaining new item fit into the public attitudes subscale. All inter-item correlations exceeded 0.3, and three-quarters of them were between 0.4 and 0.7.

The factor loading value ranged from 0.57 to 0.85 for the Stigma Scale for ALWH and 0.70 to 0.86 for

the 10-item stigma scale in our sample of ALWH. The factor loading values for the three new items on the Stigma Scale for ALWH were 0.57, 0.67, and 0.77 (Table 2).

Factor 1 (personalized stigma/disclosure) explained 51.3% of the total variance, while Factor 2 (negative self-image) explained 10.3%, and Factor 3 (public attitudes) explained 9.2% of the variance. These three factors explained 70.8% of the total variance of the Stigma Scale for ALWH.

The Cronbach's α of the Stigma Scale for ALWH was 0.92 (overall), 0.90 (personalized stigma/disclosure), 0.86 (negative self-image), and 0.83 (public attitudes). The Cronbach's α for the original 10-item stigma scale applied to our study sample was 0.90 (overall), 0.87 (personalized stigma), 0.82 (disclosure), 0.86 (negative self-image), and 0.80 (public attitudes). Thus, the Stigma Scale for ALWH had equal or higher internal consistency and reliability in our sample of ALWH, compared to the original 10-item stigma scale.

The Stigma Scale for ALWH was significantly and negatively correlated to self-reported health ($r = -0.358$, $p = .003$) and the abbreviated SL-ASIA ($r = -0.33$, $p = .006$). Meanwhile, the scale was not significantly correlated to education (high school graduate; $\beta = -0.28$, $p = .93$).

Discussion

The purpose of our study was to adapt an existing HIV stigma scale to be culturally appropriate for use with ALWH in the United States. We established the Stigma Scale for ALWH using multiple methods, including individual interviews, subject matter expert reviews, focus groups, and a cross-sectional survey.

The newly developed scale contains 13 items with three subscales. We also assessed the reliability and validity of the scale. The Stigma Scale for ALWH was negatively correlated with health status and acculturation, but not with education. These findings were consistent with previous studies and sufficient to establish the convergent validity of the scale (Emlet et al., 2013; Loutfy et al., 2012; Rajabiun et al., 2008; Sumari-de Boer et al., 2012).

The Cronbach's α for overall and subscales on the Stigma Scale for ALWH were equal to or higher than

Table 2. Factor Analysis

	Factor Correlation					
	Personalized Stigma (1) ^a /Disclosure (2) ^a		Negative Self-Image (3) ^a		Public Attitude (4) ^a	
	10-Item Stigma Scale	Stigma Scale for ALWH	10-Item Stigma Scale	Stigma Scale for ALWH	10-Item Stigma Scale	Stigma Scale for ALWH
I have stopped socializing with some people because of their reactions of my having HIV (1). ^a	0.85	0.85				
I have lost friends by telling them I have HIV (1). ^a	0.81	0.81				
I have been hurt by how people reacted to learning I have HIV (1). ^a	0.72	0.74				
I am very careful whom I tell that I have HIV (2). ^a	0.76	0.72				
I disappointed my family and feel more distant from them since telling them I have HIV. ^b		0.67				
I worry that people who know I have HIV will tell others (2). ^a	0.70	0.65				
I have a friend or family member who might know I am HIV positive, but I am afraid to ask and find out for sure. ^b		0.57				
Having HIV makes me feel unclean (3). ^a			0.85	0.83		
I feel that I am not as good a person as others because I have HIV (3). ^a			0.81	0.83		
Having HIV makes me feel that I'm a bad person (3). ^a			0.81	0.79		
Most people with HIV are rejected when others find out (4). ^a					0.86	0.84
Most people do not have enough HIV knowledge to understand me. ^b						0.77
Most people think that a person with HIV is disgusting (4). ^a					0.80	0.76

Note. ALWH = Asian(s) living with HIV.

a. 10-item stigma scale subscale assignment.

b. These items were new to the Stigma Scale for ALWH.

those of the original 10-item stigma scale applied to our study sample. These findings indicated that the new scale might more reliably capture the HIV stigma experienced by ALWH, compared to the 10-item stigma scale.

Limitations

Our study had several limitations. The Asian population in the United States includes a wide variety of ethnic groups with a number of different cultures, belief systems, and languages (CDC, 2012; Pew Research Center, 2012). Participants for our study included only a few Asian ethnic groups. The revised scale may not capture additional unique aspects for Asian populations not represented in the study. Research is needed to validate the Stigma Scale for ALWH with other subsets of Asians in the United States. Another limitation was that our study included only Asians who could read and speak English. Recent immigrants or monolingual Asians might experience HIV stigma differently. We recommend translations of the Stigma Scale for ALWH into Asian languages to test Asians who do not speak and read English. Finally, we recruited participants at an HIV-related community-based organization. All were uninsured or underinsured, and most of the participants were men who have sex with men. The study sample may not represent ALWH who are insured, financially stable, or heterosexual. A study with multiple research sites including private clinics might help us better understand the HIV stigma experienced by Asians in the United States. Finally, we cannot ignore that our study used the shortened version of the original Berger Stigma Scale and added three items that addressed unique aspects of stigma in Asians living in the United States based on the sample of ALWH. The new items might overlap with items from the original full scale; we did not conduct this analysis. Furthermore, there are several other shortened versions of the original scale that might capture the stigma experience of ALWH better than the one we used (Bunn, Solomon, Miller, & Forehand, 2007; Franke et al., 2010; Jimenez et al., 2010). Additional psychometric analysis of our stigma scale for ALWH compared to the original or shortened Berger Stigma Scale is needed.

Conclusion

To our knowledge, this is the first study to establish a culturally sensitive HIV stigma scale for ALWH in the United States. Our study revealed good reliability and validity of the Stigma Scale for the sample of ALWH. Previous studies have found that HIV stigma is related to poor health outcomes, negative well-being, and lower antiretroviral treatment adherence (Dorić, 2017; Seghatol-Eslami et al., 2017; Turan et al., 2017). The HIV Stigma Scale for ALWH might help health care providers understand the type and level of HIV stigma experienced by ALWH and provide culturally appropriate HIV care to this population.

Disclosures

The authors report no real or perceived vested interests that relate to this article that could be construed as a conflict of interest.

Key Considerations

- HIV stigma is unique to each racial and ethnic group. In order to provide culturally appropriate HIV care, health care providers need to understand the type and level of HIV stigma experienced by their patients.
- The newly developed scale, Stigma Scale for Asians Living with HIV (ALWH), addresses the unique aspect of stigma experienced by ALWH. This culturally appropriate stigma scale might help health care providers understand the HIV stigma experienced by this population.
- Research is needed to validate the stigma scale and assess stigma experienced by other subsets of Asians.

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